Sample Letter of Intent

May 6, 20xx

To the Trustee of the Special Needs Trust for Paul Sanchez:

We appreciate your future efforts on behalf of our beloved Paul and hope that you delight in him and his uniqueness as we have. We hope the following information will be helpful.

Family History

Paul has three older siblings who have always been affectionately involved in his life. We feel it is significant that each brother and his sister approached us individually years ago to ask to be his guardian if anything were to happen to us.

David Sanchez, 41 (wife Rebecca Chang, daughter Tiena Mei Sanchez, 2), 3211 Bayview Avenue, Alameda, CA 94501, 510-555-4567. Paul spends weekends with David and his family about once every six weeks and has phone contacts between visits. David often helps Paul find special DVDs he wants.

Mark Sanchez, 40 (wife Sonja Sanchez, sons Benjamin, 3, and Thomas, 1, and a child expected in a few months), 2445 Oak Avenue South, Minneapolis, MN 55405, 612-555-3219. Paul visits Mark and his family perhaps twice a year and has occasional phone conversations with Mark. Because Mark is a physician, we feel it is wise to consult him about any medical problems that Paul may have before making final treatment decisions.

Juliet Sanchez, 35 (partner Juliana Sorenstram, daughter Annika, 2, son Marcus, nine months), 815 Marcos Court, Santa Rosa, CA 95404, 707-555-9876. Juliet was a constant companion to Paul throughout his childhood, unbidden, a veritable "second mommy." Juliet and Paul share frequent phone calls. Paul spends the weekend with Juliet and her family about once per month. Among other helpful acts, Juliet is comfortable with Paul's personal needs, like helping him buy new shoes that accommodate his unusually small but wide feet, or even clipping toenails if she notices a need.

(Uncle) Steve Sanchez (wife Catherine Sanchez), P.O. Box 1750, Lakeport, CA 95453, 707-555-7895. Uncle Steve and Aunt Catherine have taken a warm and cheerful interest in Paul from his birth. One of Paul's first words was "Nunc" for "uncle." If Paul were ever to have any needs of a legal nature, we feel it would be wise to discuss them with Steve, who is an attorney.

(Cousin) Nicole Davis, 40, 1290 Eighth Street, San Francisco, CA 94122, 415-555-4369. Nicole spends time with Paul, usually at family celebrations, several times per year.

Other relatives with whom he has cordial but less frequent dealings are **Anne Davis and Richard Ross** and **Carol and Mickey Forlani** (aunts and their spouses), **Ken Sanchez and Sara Sanchez** (uncle and his wife), **Rubin Sanchez** (cousin), **Megan Sanchez** (cousin), **Dionne Davis** (cousin), and **Walter and Olivia Forlani** (cousin and wife).

General Medical History

Paul was born on July 31, 1985; he has Down syndrome. As a young child, he enjoyed good health but needed consistent medical attention for frequent ear infections, sore throats, and colds that regularly morphed into sinus infections. Fortunately he had no cardiac problems, an issue for half the children with Down syndrome. He had pneumonia two times as a child. We find that yearly flu shots and pneumonia immunization as directed by his physician are important preventive measures.

His dentition was irregular and late. His skin is very fair and he sunburns easily. He continues to need to use sunscreen daily and to wear dark glasses outdoors. He has dry skin; flaking on his face or hair is treated with Aquanil HC, an over-the-counter preparation.

When he was about 12 he had a difficult episode lasting many days of fearfully thinking he was changing into an animal. The episode faded, but as the years passed, occasionally other fears dominated his waking hours, basically unpleasant thoughts that he could not banish from his mind. When he was 17, his father (a psychiatrist) realized that Paul had a form of obsessive-compulsive disorder. Treated with Zoloft, the uncomfortable symptoms disappeared at once. He continues to take Zoloft.

As a teenager he underwent a hernia operation.

At 22, he became very ill when he was thrown abruptly from a supportive school program (work experience for a couple of hours a day and a few more hours spent learning to make his way in the community) into an eight-hour workday with a brand-new 1½-hour bus ride on either end of the already exhausting regimen. Whatever sort of illness he had resulted in a painful mouth and gum infection. He already was having some problems with his gums, and the illness greatly exacerbated them. Then began serious dental work: gum grafts that were unsuccessful, rigorous training in dental hygiene and oral rinses with Periogard, and extractions of a number of teeth. He does not wear a prosthesis because it would have to be attached to teeth that are already loosening and would hasten their loss. He now alternates appointments for cleaning and checkups between his dentist and periodontist every two months. (Contact information below.)

In his mid-20s he developed low thyroid, and now takes Levoxyl to normalize his thyroid levels. Nevertheless, he tires easily and needs significantly more rest than average. He uses Beconase inhalant to prevent sinus infections. Paul has had a lifelong tendency toward constipation. He takes mineral oil nightly to control the problem.

Paul has a high pain tolerance. If he says something is painful, it is advisable to obtain medical assistance. He may have difficulty in localizing or explaining what is happening to him physically. For example, he might say, "My throat hurts," when he is nauseated. His internist is Kent Yasuda, M.D.

None of these health issues is particularly alarming, but like most people with Down syndrome, Paul benefits greatly from regular, consistent medical and dental care.

Paul has a tendency to put on weight. We try to advise him and monitor his eating habits, but with limited success. We worry that this tendency may cause health problems eventually.

Paul has severe obstructive sleep apnea and must always sleep—naps included—with his CPAP (continuous positive air pressure) mask in place.

Some additional caveats: People with Down syndrome have a severe hypersensitivity to atropine, a substance that may be used in eye examinations and sometimes following a surgery. Doctors treating Paul should be reminded of this. People with Down syndrome have more problems with anesthesia because of "sloppy airways" due to their low muscle tone; surgery should not be lightly undertaken. Some people with Down syndrome develop weakness in their spinal cord due to atlanto-axial subluxation; Paul did not have the condition when he had spinal X-rays as a child, but it can develop later in life.

Paul handles the regimen of health measures and medicines described above on his own. He benefits from regular reminders, lists, and discussion. Often when asked, for example, if he is remembering to take his Beconase, he will say, "Oh, that's right, I forgot."

Paul had therapy and counseling for several years after some traumatic events. He enjoyed the support and benefited greatly from therapy. If he seems troubled, we would like him to have this opportunity again. It would be best to investigate which therapists are comfortable, experienced, and interested in working with Paul.

Current Medical/Dental Providers

We have always kept Paul on our medical insurance; at this time he uses Medicare and has a supplemental insurance plan from the County Health Plan. He has no dental insurance. We feel adequate medical and dental care are a priority and prefer to have Paul cared for by specialists who have treated other people with Down syndrome and are familiar with the medical needs that may accompany the syndrome.

Kent Yasuda, MD, internist, 4710 Yolanda Avenue, Santa Rosa, CA 95403; 555-8764

Robert Jeffords, DDS, dentist, 40 North Main Street, Santa Rosa, CA 95403; 555-4567

Richard Smithson, DDS, periodontist, 1416 Mountain View Lane, Santa Rosa, CA 95403; 555-6589

Education

Paul was "mainstreamed," as the practice of attending regular school classes was termed when he was a boy, until he was 17 years old. He was extremely well liked by other students, with many friendships extending to the present. He was usually supported academically by the Resource Room Specialist. He reads at about a fourth- or fifth-grade level, and writes perhaps like a third-grader. Paul can add a little and used to be able to subtract.

He developed a talent for writing unique poems. They are quite wonderful. If asked, he will write one for any occasion.

Paul's speech is often difficult to understand; his missing teeth compound the problem. Patience is sometimes required. His thought processes are much more advanced than one would expect listening to his articulation.

At 17, he began attending Special Education classes to prepare him for practical issues like work experience, bus riding, and money management. It was also an opportunity for him to have classmates who were true peers. He finished school at 22 years of age. During those years he enjoyed attending classes at Santa Rosa Junior College, and continues to talk of wishing for such an opportunity again. He lives in walking distance of SRJC, but the logistics of working during the day, doing chores with housemates when he returns home after a lengthy bus ride, and his fatigue have militated against taking more courses. He does delight in thinking of any meeting or class as a "graduate school class."

Employment

Paul has been in supported employment in the community since he was 22. He is with an enclave of several workers with a supervisor on site. We feel this situation is preferable to working alone since he takes a number of weeks of vacation, some without pay; this custom might be difficult if a business was depending only on Paul for certain services. During these approximately four weeks per year, spread out, he travels and celebrates family occasions, as when cousins visit from Sweden. We also feel it is beneficial for him to have peers who are work colleagues. It is possible that as he grows older, Paul may need a different work situation—less stressful perhaps, or perhaps with transportation provided. Time will tell.

Currently he is at Dynamat, a technology company in Rohnert Park. He does assembly work. He is accurate and quite slow compared to the average worker. His supervisor, Tom De Leon, is ideal for Paul. Paul has a tendency to become too easily offended by other people, especially authorities. Mr. De Leon is limitlessly pleasant and respectful with Paul.

The organization that currently supports Paul's employment is **North Coast Industries,** 555-9641. He takes part in the occasional social events, such as The Human Race in May and a dinner dance during the year. Generally speaking, Paul needs transportation to these and any social events. He is capable of riding the bus only on routes on which he has been trained. He rides the city and county buses to his workplace. North Coast Regional Center sends him his bus passes monthly.

At times, there have been recurrent issues of Paul's not going to work when he was not ill. We feel it is important for him to be out in the world working during the week, like everyone else. We find that giving him an allowance of spending money contingent on his going to work daily is effective. He receives $30 per week in spending money if he goes to work every day. If he does not go one day, he receives only $5 per day. So if he stayed home one day, he would receive only $20 allowance that week. Naturally if he is ill or has a conflicting engagement like a medical appointment, his allowance is not docked.

It is common for Paul to ventilate frequently about mild negatives in his life, and not comment on the positives. Therefore, it is best to pay attention, evaluate, and not react too quickly when he complains about work, his supervisor, or coworkers.

Lately he has been expressing a desire to work at Agilent Technologies, where his sister is employed, and which is near Arcangel House. Perhaps at some point he might try that, since there is a North Coast Industries work group located there that does assembly work.

In the past, Paul had jobs that involved too much heavy labor for him. For example, one job required him to lift many flats of soft drinks. He vastly prefers lighter work, more complex work, too.

Current Living Situation

Our opinion is that Paul currently needs an arrangement between an overly protective group home, where he probably would not have his own room, and living in an apartment by himself with little oversight and companionship. In our county, a continuum of alternatives was not available. Personally, we were very happy living with Paul, but for many years he had been saying, "I want to move out. I want to be independent."

When he was 25, Jane Ford, a lifelong friend and advocate for Paul, called to say, "You know that project we are always talking about for Paul? I'm ready to do it." What a surprise! Jane bought a house, 4567 Arcangel Avenue, in Santa Rosa, perfectly located near shops, markets, Santa Rosa Junior College, the Recreation Center, and buses. It is even across the street from a workshop for more involved people with special needs, so there are speed bumps in the street for safety. And wonderfully, the house is only two miles from our home and his sister Juliet's home. After living at Arcangel House for five weeks, Paul came home to celebrate Passover with all of us. He pointed to the place on the kitchen doorjamb where we have never painted over the dates and heights of our children. "Dad, you've got to measure me again. I'm tall now."

After a few years, Jane Ford wished to sell the house; we bought it so that the situation, which by then we knew worked so well for Paul and his housemates, could continue. The house has three bedrooms, two baths, and a modest garage apartment. Paul lives there with two other people his age who happen to have different special needs, but function roughly about like Paul. Paul has a voucher from HUD from the City of Santa Rosa, which means that he pays up to one third of his income (including Social Security) for rent. The housing authority pays the difference. Right now, his rent is $500, of which he pays around $200.

He and his housemates are supported by a person, currently Cheryl Frost, who lives rent free in the garage apartment. She earns money by being the three housemates' IHSS (In-Home Supportive Services) worker. She helps organize housekeeping chores among the housemates, cooks their evening meal, and generally stays in tune with how their lives are going. **Oaks of**

Hebron (555-5927) is an organization that supports the housemates too, by assigning a Community Support Facilitator (CSF) who is available to Paul, and who visits him weekly, helps him pay bills or straighten out problems with the buses—generally is available to help solve problems as they arise. The CSF also may take him to medical or dental appointments. It has been our practice to be at such appointments also, and we usually drive Paul home afterwards.

In Paul's situation, the caregivers can purchase food at the Food Bank, so Paul pays only $150 per month for food. We like to supplement this weekly by buying him melon (cut into chunks), cottage cheese, eight cans of tomato juice, and a bag of romaine lettuce. We do so because he needs low-calorie alternatives to help him control his weight, and because he needs fruit and vegetables in some quantity to help with his chronic constipation.

As is his wont, Paul often complains about aspects of his living situation. We find it best to listen and let him express his feelings, even though we usually judge that his living situation, or job situation, or relationship situation is probably optimal. Paul is not apt to tell us about the positive aspects of his life, for some idiosyncratic reason. He may say he "wants to live in the apartments in Rohnert Park." These are individual apartments for people with special needs with no one permanently on site if a need arises. We do not feel that this situation is safe for Paul over the long haul. We feel he needs more support, especially since he has always had and continues to have difficulty saying "no" to any suggestions by others, which could lead obviously to dangerous situations.

It is possible that Paul may need a more supportive environment, probably a group home, as he grows older. If he were to develop a condition such as diabetes, we would definitely want him to live in a group home where his increased medical needs could be met.

Day-to-Day Routines

Paul is quite self-sufficient. He rises and prepares himself for his workday independently. He fixes his own breakfast, packs a lunch, and walks to the bus stop by 7:30 a.m. He takes the bus to work and begins work at 8:30 or so. He wears a fanny pack with identification, bus passes, cell phone, and

dark glasses. He has a backpack with his lunch and other necessaries like his treasured Walkman and favorite Beatles tapes.

Because Paul fatigues more readily than the average person, we have had his workday shortened. He walks to the bus stop to catch a bus home around 2 p.m. He arrives home, walking from the bus stop around 3 p.m. He then does assigned household chores, like sweeping and mopping the floors. Whoever is living in the garage apartment prepares dinner for the household and the four of them share the meal.

Paul is accustomed to calling us each evening at around 7 p.m. This is his own idea, though we admit we find it pleasant. He likes to recount a little about his day and his thoughts. It is perhaps a ten-minute chat. We feel happy that his living "on his own" has not lessened the affectionate connection that we have with him.

In the evening, he listens to his music collection or looks at a video or DVD. He and his fiancee Annie share a phone call.

He does his own laundry weekly. Paul likes to wear all clean clothes daily.

He is well groomed. He needs occasional reminders about what to do about, say, flaking scalp.

On weekends, he often visits a family member or his fiancee. He may attend a movie or a party, perhaps with housemates. He doesn't mind being in his home (Arcangel House) on weekends; actually he likes it. On Sundays, he likes to be there shortly after midday to make a transition to the upcoming workweek.

Paul has a longtime interest in and detailed knowledge of the Beatles, especially John Lennon. He likes to purchase tapes, books, videos, and DVDs, plus the occasional T-shirt about the Beatles or other topics. He likes to pore over books about the Beatles. He used to write poetry, and will do so now if encouraged.

He needs to exercise, but tires quickly on long walks or lap swimming. Something is better than nothing, we feel. He does better if the exercise is incorporated in his day—for example, walking to and from the bus stops.

Paul enjoys most foods. He always has, even as a small child.

Social Environment

Paul has always been a well-liked person. He dated frequently as a teenager. He is in a romantic relationship with **Princess** (called **"Annie"**) **Priest** (Eddington Hall Apartments, Rohnert Park; 555-7693). We strongly feel that their relationship should be celebrated, but we do not believe that the couple should live together or marry. Paul and Annie seem to get along best when they spend most of a weekend together. Longer contact results in quarreling. Paul spends part of a weekend with Annie about two times per month. We regard Annie as a daughter-in-law; she attends most family celebrations.

As stated above, Paul has frequent and loving contacts with his brothers and sister and their families. He has developed skills in relating to his young nephews and nieces.

Lejf Jensen is a few years younger than Paul; they have been lifelong friends. They continue to see each other socially several times per year. Usually they do an activity together and share a meal somewhere. Lejf is currently a disc jockey at "Four More," a trendy radio station in San Francisco; he also works as a substitute special education teacher.

Matt Conrack is a friend since elementary school. Paul visited him in New York last year, where he was in graduate school. Again, they have cordial social contacts several times per year—usually an outing and a meal together.

Pat and Cassie Garcia, brother and sister, were neighborhood playmates when they were all toddlers together. They remain interested in Paul and sometimes contact and visit him.

Any of these friends would probably need help in setting up a social contact with Paul. If Paul received a phone message, he would not be able to call the person back on his own (although he can do so with family members who are in the speed dial of his phone).

Currently, it seems difficult for Paul to mix socializing and working. Activities that take place during the workweek are too much for him. He thinks of social activities as taking place on the weekend.

Paul usually says "no" if asked if he wants to do something, especially something social. This is a knee-jerk first reaction to most suggestions of any kind, and should not be taken too seriously. We try to help him keep his social life going by encouraging, sometimes almost insisting, that he take part in a social activity. Maybe one or two per weekend. He is often tired after two or three hours at a social event, and it is reasonable for him to return home then if he wishes to.

We believe it is important for him to interact with friends who also have special needs. He and Annie often double-date with Brent North and Julia South, who live in the same apartments as Annie. Her apartment is located near many restaurants and a cineplex, allowing them to choose independently.

In recent years, Paul (and usually Annie) have been delightedly participating in wonderful, low-cost travels arranged by Jane Ford, an old friend, and her organization. This year he is traveling to the Grand Canyon next month, and will cruise the Inside Passage of Alaska in the fall. Many of the same people are present on each trip. The group also went Christmas shopping in San Francisco this year. Paul considers it "his club." We hope this opportunity will continue.

There are others in the community who understand Paul and his needs from long years of contact and experience. They would be available to consult.

Sue Lake, MA, special education teacher (4672 Alejandro Drive, Santa Rosa, CA 95404; 555-4691), was his infant teacher and has remained in close contact with us. A great deal of problem solving around issues that have arisen for Paul has included Sue's views.

Nancy Fernandez (9420 Glencannon Drive, Santa Rosa, CA 95405; 555-9321) is a longtime friend as well as the mother of Lejf Jensen. She is a special education teacher too. Again, problem solving for Paul usually includes her suggestions.

Nancy Barlotti, RN, (679 Purrington Road, Petaluma, CA 94952; 555-0368), is a fellow parent of a person with special needs very different from Paul's and a former coworker in Early Intervention. Her perspective on Paul is wise.

Jane Ford, MSW, who originally bought Arcangel House where Paul lives, and who runs the trips for him and others, has known Paul all his life. Her views on any issues would be helpful.

Travel

Sometimes Paul flies to visit friends or relatives. He travels with a family member or on his own. When he flies alone, we buy what the airlines call their "unaccompanied minor program." This means that a staff person on board is assigned to be available to Paul if he needs help, or if the plane must change its itinerary due to weather or another exigency. Paul will be released only to the person whose name is given before Paul boards the plane. Under the program, whoever takes him to the airport or comes to pick him up is allowed through security to the gate. When he flies with a family member, we pay the family member the same amount of money for any supervision that may be helpful to Paul.

Religious Proclivities

As an interfaith family, we have always observed and celebrated both Jewish and Christian holidays. Very occasionally Paul attends First Methodist Church with me. He also participates with Oaks of Hebron personnel in occasional religious activities.

Preferences for Funeral Arrangements: We find it difficult to address this topic for one of our children, but here goes: We would like Paul to participate in organ donation, but are not sure if that is possible if a person has a different number of chromosomes from the average, as is the case with Paul's form of Down syndrome.

Arrangements should be whatever the surviving family deems appropriate. Perhaps a memorial service in a Methodist church or Jewish temple with spoken tributes from those of us who have loved him so, as well as thoughts from a clergyman. Certainly any service should include lots of Beatles music. We would very much like to have him laid to rest near us, his parents; we fervently hope he will never be far from us. Probably cremation is suitable. An informal family celebration of his life, with Beatles music and a buffet, might follow the service.

Other Relevant Information

Paul has a talent for choosing gifts for family and friends, as well as for planning parties.

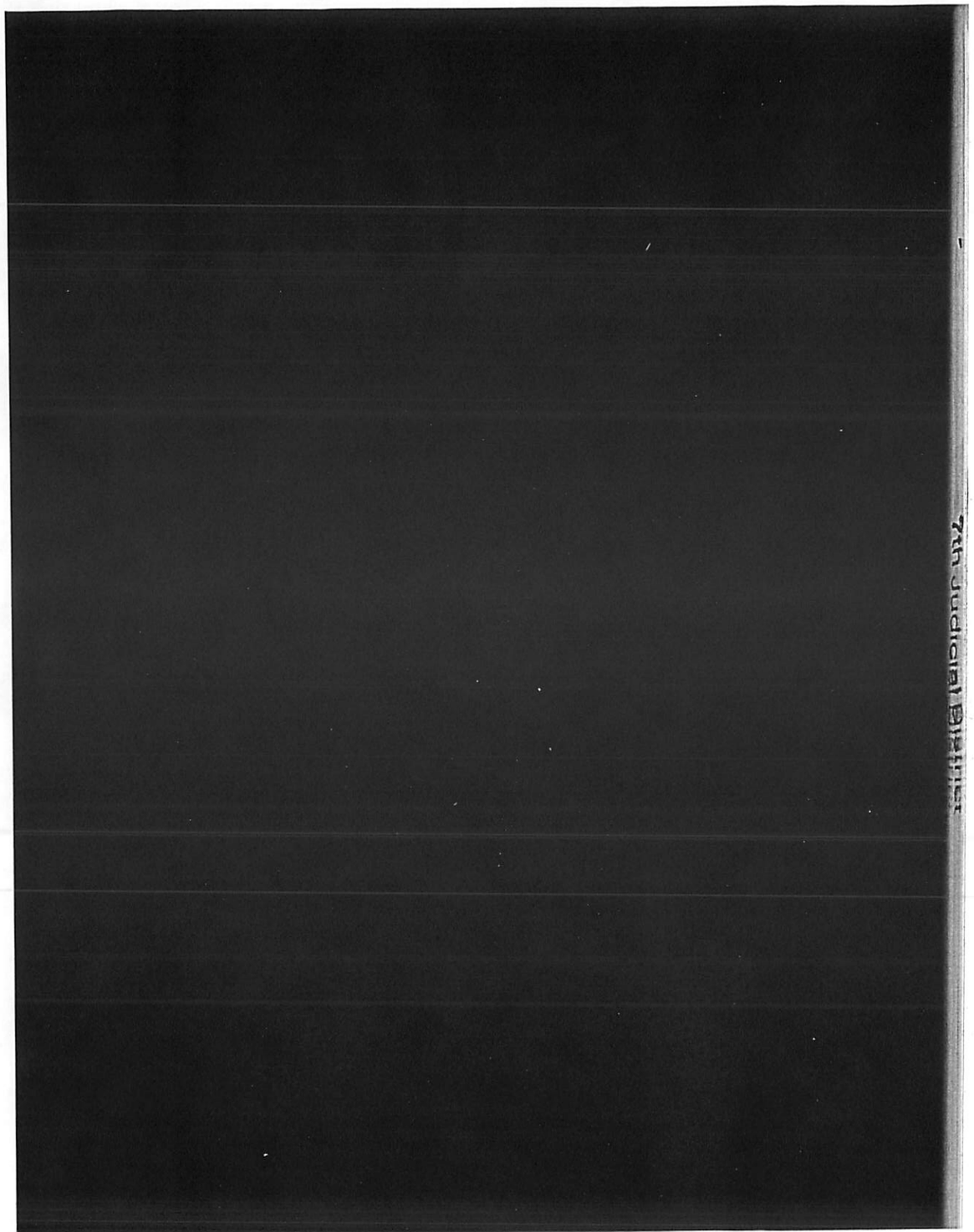
Paul loves to have the opportunity to "be in charge" or be given a responsibility. For example, he was happy when he could volunteer at the Recreation Center, serving soft drinks. Sometimes when he travels with a small group, he is in charge of keeping track of the suitcases, or of calling everyone for dinner.

Paul is unfailingly punctual (far better than his mother); he organizes his belongings neatly; he remembers all appointments and engagements, and keeps an accurate calendar. He has an excellent memory for people, and for details about them like their birthdays (or even "half-birthdays").

He understands which amounts are more or less as far as money, but needs significant guidance in managing finances. Paul does not have a conservator, so it is necessary to obtain his cooperation through explanation and discussion regarding both medical treatment and financial management.

Paul cannot say something that is untrue, for example to manipulate a person or situation; he doesn't understand the concept. It may be important to know, however, that if he is asked a direct question, such as "Why did you do that?" he will probably interpret it as a demand for an answer. His response then will be his best guess, but he does not use niceties of expression like, "Well, it may have been because...." His answer will sound like a statement, because that is the syntax he understands how to use. This statement may not be accurate, but simply his effort at pleasing with a required response. Also, if he is worried about something, he may state it as a fact. He might say, "My supervisor said I have to get a new job," when what he really means is, "My supervisor reprimanded me today and I am worried that if he is mad at me maybe he won't want me to work here."

Paul is a lifelong client of **North Coast Regional Center.** A specific Client Program Coordinator, currently Dorothy Merriwhether, is assigned to him and available to discuss and help solve issues that arise.



If Paul disapproves of a comment or an opinion we express, he may hang up the phone or storm off angrily. After about ten minutes, he will return to discuss the matter calmly and without anger. He is reasonable and ultimately open to support in the form of suggestions presented in a friendly manner.

We hope you find this account helpful. Paul's welfare has been a priority for our family all his life. We are now entrusting his welfare to you.

Sincerely,

Lois and Bob Sanchez